## Meeting Maxford

Joan Cronk

Conceiving a child isn't a very complicated process at all. Dad contributes 23 chromosomes and so does Mom, the sperm meets the egg and BINGO, you have a child. Sometimes, though, the whole shebang goes haywire and there is the presence of one extra chromosome—just one chromosome—and everything changes. Nothing is ever the same again.

That is what happened in our family when my grandson, Maxford, was born with Down syndrome in 2004.

I'm ashamed of some of the thoughts I had in those early, sad days. I'm ashamed that when I was alone with Maxford I snuck a look at the palms of his hands, looking for the telltale line that ran across children's hands born with DS. I'm ashamed that I hated every single parent on the OB floor whose kid had been born "typical." I'm ashamed I wanted to be anyone else, just not me.

I'm ashamed that I called everyone I knew during the time the blood test was being evaluated and begged them, in a voice held together with hope, "Just pray it isn't Down syndrome."

I'm ashamed that I hated the doctor who gave us the news, the words spilling out of her mouth and me wanting to scream, "Take it back! Take it back!"

I'm ashamed that I didn't embrace the situation more quickly, and move from anger to acceptance in a heartbeat, instead of over a period of time. Instead I was limp with fear and concern.

When parents give birth to a typical child, they realize their disappointments at a tolerable rate. Maybe their child doesn't get invited to birthday parties or doesn't make the team. Come college time, he or she isn't accepted into a great university. But when a child with special needs is born into a family, they realize their disappointments all in one day.

Families who had early information during their pregnancy about the birth of a child with special needs did a lot better than we did. For us, it all began on the day of Maxford's birth.

My son was the first one to receive the news after the doctor steered him into a little room and he sat on a tiny stool, listening to the words that would shape his life. I can't imagine what it was like for him; I wish I had been there to hold his hand.

But life does go on and we did survive those first few months, and Maxford did well. He was born with no health issues and with a strong heart, which is a huge bonus for kids with DS.

Maxford started going to school at the University of Washington Experimental Education Unit (EEU) when he was one month old. At EEU there are no labels, just a whole lot of kids learning together. Some are typical and others have special needs, and they are thrown together in this wonderful salad bowl of learning and playing. From that moment on Maxford was part of the team.

No first day tears for this kid; he has grown up attending school three times a week. This school year he began attending school every single day.

The bus picks him up right at his front door, and he is ready to rock and roll, wearing his Elmo backpack and his favorite baseball hat.

Maxford's handicap is obvious, but the rest of us, well, we hide our handicaps. We cover our shyness with a glass of wine at a social function until we're ready to move in and be part of the group, knowing no one really noticed we were worried or awkward. They didn't see our handicap.

Ted Bundy had a handicap, and for a time no one could see that either. He was such a good-looking guy. His handicap was hidden too.

But Maxford, well, his handicap is pretty darn visible. At 100 yards you know this kid is different. He wears the mask of a child born with DS and there is no doubt about it. That was one of the tough parts. Maxford's sweet face is an open invitation. He has no preconceived notions about how people will relate to him.

In the beginning, when we were still raw with pain and confusion, people stared. Sometimes they whispered. I wanted to run after them and yell, "Take a good look, just take a good look," but I didn't. Instead we retreated. We cried because we were different.

Well-meaning friends said things like, "Oh you'll see this as a blessing someday," and finally in anger I shot back, "Well let's just have this blessing in your family then, and not mine."

But Maxford is a blessing. The DS is not, but Maxford is. He is such a cool kid. Because his verbal skills are delayed, he currently struggles with words, but he rocks with sign language. His "vocabulary" probably numbers up to 60 words, and if you can understand his sign, he can communicate with you. I'm pretty good at it, although there was that one awkward time when I was in charge and he signed "toy" which I took for "potty" and so we spent a lot of time in the bathroom, with Maxford probably wondering which one of us had special needs!

He loves books and will sit for long periods of time looking at the pages, his little feet crossed in front of him. He wears glasses and they have given him this snappy Ivy League look that we love.

His mom and dad dress him in the preppiest of clothes. No hand-me-downs for this kid. We can't risk that, he has to look better than most. You do that when you have a child with special needs.

I've learned that the pain never goes away, that I'll always wish that Maxford was typical. However, my expectations have shifted. I've accepted the DS and now I pray that someday he will have a job that he loves and maybe someone to share his life with. I pray that he will live independently. I pray that he is able to attend college.

I know that he probably will never drive a car or father a child, but he won't be packing a gun and flying off to fight a war. He won't pick fights and he will have a lot of friends.

When people see Maxford walking down the street with his loving family they may take a second look, but by the time they round the corner, I'll just bet they are whispering to each other, "What a lucky little boy." And that he is.